DOCUMENT RESUME

ED 294 352 EC 202 521

TITLE Focal Point. Volume 1, Fall 1986--Spring/Summer 1987.

INSTITUTION Portland State Univ., Oreg. Regional Research Inst. for Human Services.

SPONS AGENCY National Inst. of Handicapped Research (ED), Washington, D.C.; National Inst. of Mental Health (DHHS), Bethesda, Md.

PUB DATE 87

NOTE 37p.; Bulletin of the Research and Training Center to Improve Services for Seriously Emotionally Handicapped Children and Their Families.

PUB TYPE Collected Works - Serials (022) -- Reports - Descriptive (141)

JOURNAL CIT Focal Point; v1 n1-3 Fall 1986-Spr-Sum 1987

EDRS PRICE MF01/PC02 Plus Postage.

DESCRIPTORS Agency Cooperation; Child Advocacy; Conferences; Delivery Systems; Education Work Relationship; Elementary Secondary Education; *Emotional Disturbances; Family Role; Program Implementation; Rehabilitation; Severe Disabilities; Transitional Programs

ABSTRACT

The document contains three issues of the newsletter of the Research and Training Center to Improve Services for Seriously Emotionally Handicapped Children and Their Families. The first issue is introduced with an article titled "Re-Thinking Emotional Disturbances in Children," by Thomas M. Young. Topics covered include the following: issues raised by the Child and Adolescent Service System Program initiative; the Therapeutic Case Advocacy Project; the Youth in Transition Project; the Families as Allies Project; current activities of states involved in the Families as Allies Conference; rehabilitative services within the Child and Adolescent Service System Program; components of the Therapeutic Case Advocacy approach; and interagency collaborative efforts. (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

FOCAL POINT

EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.
"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
MC The Mannus
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

ED294352

RE-THINKING EMOTIONAL DISTURBANCES IN CHILDREN

by Thomas M. Young, Ph.D.

Four issues raised by the Child and Adolescent Service System Program (CASSP) initiative

What is the nature of emotional disturbances in children?

The nature of what we customarily have referred to as "emotional disturbance" or "mental illness" in children is not signified adequately by those phrases. It appears on the basis of accumulated practice experience and research (especially longitudinal research) that what we refer to as "emotional disturbance" or "mental illness" in children is more accurately described as behavior that is disturbing to those who have to live with it.

Case examples, when viewed in the context of the more recent advances in understanding and treating children considered emotionally disturbed, have led us here at the Portland State University Research and Training Center to change our own terminology regarding children considered emotionally disturbed. We prefer the phrase "emotionally handicapped" because we believe it helps us shift our focus from the child-as-problem to the context-as-solution. It emphasizes that emotionally handicapped children are special children with special needs requiring special environments - specifically, ones that can accommodate, adjust to, or compensate for their disability.

This, it turns out, is consistent with the World Health Organization's perspective on disabilities as impairments that are defined in terms of their functional consequences in specific settings. Since we are concerned with improving services for emotionally handicapped children and their families, we are concentrating on research and training activities designed to help parents, teachers, employers and the helping professions find ways of modifying living, learning and working environments to accommodate, adjust to and compensate for children with emotional disabilities.

The CASSP initiative still refers to its target population as seriously emotionally disturbed children and adolescents. This is a questionable practice that should not be encouraged to continue under federal auspices. Continued use of this terminology will allow the CASSP initiative to be considered only as a "mental health" program in a very narrow sense, namely, one that funds and facilitates the application of intrapsychic treatment techniques to children and adolescents. All of CASSP's efforts at systems change will founder at the service delivery level unless new thinking emerges to guide the creation of new forms of intervention that focus on ways of modifying environments so that children are no longer handicapped by their emotional disabilities in those contexts. New thinking and new forms of intervention will not develop if we all continue to use the old words and phrases. And this brings us to the second issue.

continued on page 8

RESEARCH AND TRAINING CENTER
Barbara J. Friesen, Ph.D., Director

Families as Allies Project
Barbara J. Friesen, Ph.D.,
Principal Investigator

Therapeutic Case Advocacy Project
Thomas M. Young, Ph.D.,
Principal Investigator
James L. Mason, B.S.,
Project Manager

Youth in Transition Project
Matthew J. Modrcin, Ph.D.,
Principal Investigator

Resource Services
Marilyn C. McManus, J.D., Coordinator

Focal Point
Marilyn C. McManus, J.D., Editor

Center Associates
Richard B. Black, M.S.W.
Paul E. Koren, Ph.D.
A. Christina Rutland, B.S.
E. Darey Shell, B.S.
Janis K. Worthington
Katie S. Yoakum, B.S.

GRADUATE SCHOOL OF SOCIAL WORK
Bernard Ross, Ph.D., Dean

REGIONAL RESEARCH INSTITUTE
Arthur C. Emlen, Ph.D., Director

Research and Training Center
Regional Research Institute
Portland State University
P.O. Box 751
Portland, Oregon 97207
(503) 229-4040

Copyright©1986 by Regional Research Institute
All Rights Reserved

We invite our audience to submit letters and comments.

FROM THE EDITOR

This is the first issue of a bulletin published by the Portland State University Research and Training Center to Improve Services for Seriously Emotionally Handicapped Children and Their Families. The center is funded by the National Institute for Handicapped Research (NIHR) and the National Institute of Mental Health (NIMH).

The primary activities of the center are:

1. to conduct research on ways of improving services to help emotionally handicapped children and youth to live at home, learn in school, and succeed at paid employment;
2. to develop training materials and programs for professionals, parents and employers; and
3. to serve as a resource center for other individuals and organizations working on behalf of emotionally handicapped children and their families.

The specific thrust of this initial publication is to introduce you to the center and its primary activities. There are three major center projects: Families as Allies, Youth in Transition and Therapeutic Case Advocacy. Each of these projects is described in separate articles in this issue of the newsletter. In addition, we have a lead article by Tom Young titled "Re-Thinking Emotional Disturbances in Children." This article should be thought provoking and we hope that it will elicit thoughtful responses to the issues raised by Dr. Young.

It is our intent to publish the bulletin on a quarterly basis. Each issue will revolve around a specific subject area. We plan to elicit guest articles related to the primary subject area of the newsletter. For example, the next bulletin will address issues of parent-professional collaboration in providing services to seriously emotionally handicapped children and youth. More detail is provided on page 5. We are excited about the progress of the Research and Training Center and its activities. We invite your comments and criticisms regarding the issues and concerns raised in this publication.

3

CENTER PROFILES

THERAPEUTIC CASE ADVOCACY PROJECT

The Therapeutic Case Advocacy (TCA) Project is in its second year and has been warmly received by a variety of agencies, organizations and institutions that serve many of Oregon's seriously emotionally handicapped youth and their families. The project is developing a model for delivering services to this population which combines three integral components:

1. case management;
2. case advocacy; and
3. interpersonal therapeutic skills.

The goal of the service delivery model is to provide a "system of care" for each case that comprehensively addresses the needs of emotionally handicapped youth and their families.

It became apparent quite early in the project that a model would need to be applicable in more than one context. Hence, a model of therapeutic case advocacy, while utilizing the aforementioned components, must have the flexibility to make its appeal fairly widespread.

Two separate contexts were established for developing such a model: one approach involves structuring the model for use within a given agency (e.g., child welfare, juvenile justice, public school, or a mental health facility); and a second approach involves a model that can operate among a variety of agencies which serve a given client.

Both approaches of the model are being developed in conjunction with individuals and agencies who have had extensive experience in serving this troubled population. This will help facilitate the transition of therapeutic case advocacy from a conceptual or theoretical perspective to a practical or applicable set of procedures.

The model and its development will also benefit by receiving input from a national, as well as a local, advisory panel--each group possessing a broad range of expertise in serving emotionally handicapped youth. Included among local advisors are an attorney, an advocate, a state hospital outreach coordinator, a mental health facility executive director, an administrator from the county juvenile court, a county mental health program specialist, and a unit manager from the local branch of the state Children's Services Division. This range of representation will help in the formation and utilization of therapeutic case advocacy locally.

In any form of therapeutic case advocacy the idea of restructuring the youth's environment and related role players is of key importance. This does not imply forsaking the search for a medical or psychological cure; however, it presents the system of care approach as the primary focus of treating the emotional handicap.

The individuals and agencies with whom we are working have graciously welcomed the project. Collaboration will allow the development of a viable model of therapeutic case advocacy which utilizes techniques and practice skills already mastered by professionals. Therefore, collaboration will permit an easy transition from the drawing board to actual service delivery. Moreover, working collaboratively enhances the project's potential to identify and access resources, to identify systemic barriers to good practice, to expand networks and working relationships, and to provide technical assistance to local service providers. This has created an enthusiasm among administrators, managers, and line staff in youth and family serving agencies.

Currently several projects are in the works. Our model of therapeutic case advocacy is being tested in a child welfare

A comprehensive system of care approach for treating emotional handicaps

agency and will be tested in two mental health facilities in the near future. Drafts of the *TCA Worker's Handbook*, the *TCA Workbook* and the *TCA Manual* are available. These materials will undergo a year of field testing and will be revised to reflect our experiences in the field. An outline of the *TCA Parent's Guide* has been developed and the first draft of this guide is available as well. An annotated bibliography of advocacy has been published and is available through our Resource Service; addendums will be available as the bibliography is expanded. The project staff is making plans for a TCA Training Videotape that could be used by workers across disciplines and fields of practice. This videotape may prove valuable to parents and families of seriously emotionally handicapped children and will be available in mid-1987.

The future of the project will involve evaluation of the model of therapeutic case advocacy and the efficacy of the training materials produced. This evaluation of the model and training materials will not be restricted to the Oregon community. Indeed, to insure that the model will have widespread appeal, test sites are currently being considered outside Oregon. Conceptually the approach appears both viable and cost effective; however, generalizing the results must occur to determine reliability, validity and overall credibility of the model.

YOUTH IN TRANSITION PROJECT

The Youth in Transition (YIT) Project is a relatively new undertaking of the Research and Training Center. The project was initiated during the 1985-86 funding year. The original intent of the project was to employ a psychological rehabilitation model developed by Dr. William Anthony and his associates at Boston University's Center for Rehabilitation Research and Training in Mental Health. While designed for use with adults, we wanted to explore the model's applicability to adolescents who are emotionally handicapped and in the process of moving from youth serving systems to adult roles in the community. As the YIT project has evolved during the past year and our awareness of the transition issues faced by emotionally handicapped adolescents and their families has increased, our conceptualization of transition programming and intervention strategies which have an impact on the service needs of this population has broadened.

The psychiatric rehabilitation model continues to serve as a guide for the YIT Project. However, a literature review of alternative models of service delivery revealed that the psychiatric rehabilitation model was only one of many approaches available which may be employed with emotionally handicapped adolescents in transition.

In addition, important issues have emerged which will influence the nature of our work and the eventual products of the project. These issues include:

1. an increased awareness of the variety of transition programs and approaches currently being used by professionals in special education, mental health and vocational settings with the developmentally disabled;
2. the need for an articulated transition philosophy to be used by state and program planners as a guide for transition services;
3. the need for an initial assessment of exemplary transition programs in order to refine the concept of transition oriented services for emotionally handicapped adolescents; and
4. the lack of literature oriented to the transition needs of emotionally handicapped adolescents.

Programming and intervention strategies for emotionally handicapped adolescents moving from youth serving systems to adult roles

The concept of transition is complex and must be addressed from a variety of perspectives. We are defining transition as a progressive, developmental process towards the assumption of adult role responsibilities. Inherent in this definition are the accomplishment of adolescent developmental tasks and the acquisition of functional skills for role assumption in three primary environmental dimensions. These dimensions include:

1. the social and interpersonal environment;
2. the employment and/or educational setting; and
3. the daily living environment (Halpern, 1979).

We view these three environmental dimensions as interrelated and inseparable when designing and implementing transition oriented programs. Transition programs must address all three dimensions in the services which are provided, and must be anchored in terms of teaching and skill building towards the next progressive step in the transition process. In essence, transition programs must be outcome oriented rather than cure or symptom oriented. In addition, many adolescents who are emotionally handicapped face a second transition: from institutional settings to community alternatives.

The professional literature is beginning to indicate that in order to minimize re-institutionalization, the most normalized community options must be used. This information directs us to the need for a transition oriented philosophy throughout the system of care for children, adolescents and their families, which has implications for both professionals providing services to this vulnerable population and planners designing service delivery programs.

Our proposed activities for the 1986-1987 project year will address areas of advocacy, information dissemination, and an intervention based philosophy and conceptualization of transition oriented service delivery. Specifically, next year's project goals are:

1. to advocate for the incorporation of transition oriented services at both the planning and program levels of service delivery;
2. to continue refinement and begin evaluation of a transition oriented philosophy and intervention model that address the transition needs of emotionally handicapped adolescents and their families; and
3. to provide state and treatment program consultation in order to coordinate a transition oriented approach between special education, vocational rehabilitation, mental health, child welfare, and juvenile justice agencies on behalf of emotionally handicapped adolescents.

An annotated bibliography describing treatment programs, curriculum strategies and intervention approaches to impact the transition needs of adolescents is now available. Program planners will find this information helpful in designing transition programs. A transition oriented philosophy guided by a principal based approach to service delivery will be implemented in a residential program in the Portland area this fall. An evaluation mechanism will be part of this project in order to assess the initial viability of the approach. This information will be helpful to further articulate the concept of transition as it applies to the emotionally handicapped adolescent.

Reference

1. Halpern, A.S. (1979). Adolescents and Young Adults. *Exceptional Children*, 45 (7), 518-523.

FAMILIES AS ALLIES PROJECT

The Families as Allies Project reflects a particular set of beliefs about what the relationship between professionals and families of seriously emotionally handicapped children should be. The project is designed with the idea that the interests of these children will be best served if their parents and the service providers with whom they are involved work together as partners on their behalf. This collaboration should focus on developing the very best educational and treatment program for each child within the best possible service delivery system that can be put together.

Background

Relationships between parents and service-providing professionals have taken many forms over the years. Since the first recognition that emotional disturbance can and does exist among children, ideas about the causes and proper treatment of emotional disorders have influenced the relationships between professionals and family members.

Different theories about the etiology of emotional handicaps cast parents in a variety of roles, both as perceived by helping professionals and in their own eyes. For example, explanations of cause that emphasize the importance of early childhood experiences tend to portray parents as (usually unwitting) villains. In other words, parents have somehow, out of ignorance or even malice, either failed to create the conditions necessary for the optimum growth of their child, or have allowed damaging events to be a part of the child's experience. From this point of view it may be difficult for professionals, who have chosen to dedicate their lives to other people's children, to see parents as other than sick or, at best, inadequate. Interventions developed from this perspective range from family therapy strategies designed to change pathological family patterns to actions such as removing children from their (presumably pathogenic) homes. Parents as well as their children may be seen as "patients" in need of treatment. Whatever steps are taken, a result of this perspective for many families may be a sense of guilt and shame associated with the belief that they have somehow caused their child's problems. Additionally, parents may feel misunderstood, alienated and, at times, resentful of professionals' attitudes and actions.

In contrast, theories featuring an organic explanation for childhood emotional disorders often cast the parents, along with their children, as unfortunate victims of poorly understood biological malfunctions. In this scenario, parents are likely to be seen as potential "clients" in need of service and support. The link between theories of causation, models of treatment and the way parents and professionals relate to each other may not be as direct as is suggested here, and it is certainly not as simple. The main point, however, cannnot be denied: the relationship between parents of seriously emotionally handicapped children and representatives of the helping professions has often been uneasy. Parents have looked to experts for answers and solutions and have been disappointed. Professionals have often been frustrated by what appears to them to be a lack of motivation, resistance to treatment, or other uncooperative behavior on the part of family members.

The Families as Allies Project is aimed at achieving a more balanced and productive relationship between family members and service providing professionals. The project is designed to study the parent-professional relationship and to develop and teach ways that professionals and family members can join forces to promote positive change for children.

With regard to the etiology of emotional handicaps, the Families as Allies Project does not embrace a particular perspective or theoretical orientation. The evidence to support any theory is far from overwhelming. In addition, knowledge about causation is often irrelevant to the development of ways to promote the growth and rehabilitation of handicapped children and adolescents. The project does, however, operate from an assumption with regard to theories that may cause professionals to blame parents or parents to blame themselves for a child's misfortune: *even if they are true, they are not useful.*

Parent-professional collaboration toward improving services for seriously emotionally handicapped children and their families

Project Activities

Survey of Parent Organizations. We have completed a nationwide survey of self-help, support and advocacy groups that include parents of seriously emotionally handicapped children among their members. We conducted telephone interviews with over 200 groups across the country. A preliminary report of these research findings is available through our Resource Service.

Parent Organization Directory. Using information gathered from the survey, a national directory of parent organizations has been published and is also available through the Resource Service. Addendums to the directory will be published regularly as we receive information on more organizations. We think the directory will be useful to parents and professionals alike.

Annotated Bibliography. We have compiled an extensive annotated bibliography of the literature addressing the relationship between professionals and families of handicapped children. The bibliography also contains literature pertaining to parent self-help, support and advocacy groups. We found a wide variety of groups described in the published literature. Some of them were organized by professionals; others were initiated solely by parents. Copies of this bibliography may be obtained through the Resource Service.

Finding Kindred Programs. Through the parent organization survey and other avenues, we have discovered a number of innovative and exciting programs with goals that complement those of our project. Many parent organizations conduct training designed to help professionals understand the needs and feelings of parents of handicapped children. Some of this training is conducted jointly by parent-professional teams that model the collaboration they advocate. We plan to feature some of these programs in future issues of this bulletin.

Networking. Although not included as a formal goal in the original plan for the Families as Allies Project, linking people with common interests and needs has turned out to be an important project function. In particular, our activities related to the parent organization survey have stimulated a number of requests for referrals from people who want to start parent support groups.

Curriculum Development. We recently funded two curriculum development projects. The Parents, Let's Unite for Kids (PLUK) project of the Montana Center for Handicapped Children, in Billings, is developing a curriculum designed to promote collaboration between professionals and parents and to promote systems change on behalf of seriously emotionally handicapped children and youth. A second curriculum is being developed by the Parent Advocacy Coalition for Educational Rights (PACER) Center, Inc., in Minneapolis. They are producing a videotape which is also aimed at promoting collaboration between parents and professionals. Both curricula are expected to be in place in early 1987.

Parent-Professional Conference. In April, 1986, the Research and Training Center hosted a conference in Portland, Oregon. Its purpose was to promote collaboration between parents and professionals. The conference was attended by delegations of parents and professionals from each of thirteen western states. These delegations engaged in a process of developing collaborative strategies which they have begun to share with others and use in their home states.

The conference format was designed to serve as a prototype for similar meetings in other parts of the country. Such conferences are being planned for the southeast region for the winter of 1986-87, the north central region for the spring of 1987, and other regions for late 1987 and early 1988.

Complete proceedings of the western conference are available through our Resource Service. A summary of the conference will be featured in the next issue of this publication.

Rethinking Emotional Disturbances
continued from page 1

Where are the children considered "seriously emotionally disturbed"?

This is a serious political problem. Most of the CASSP target population is already in the care of other systems (education, child welfare, juvenile justice) with their own legal mandates that typically do *not* include the provision of mental health services--meaning typically, individual, group or family counseling/therapy by an accredited or certified mental health professional. Unless the CASSP initiative (at both federal and state levels of government) redefines what constitute mental health services, we can expect that all CASSP will produce is a more efficient method of referring or transferring responsibility for seriously emotionally handicapped children and adolescents to existing community mental health centers and state hospital units for children.

If, on the other hand, the mental health system (through CASSP) can redefine what constitute "mental health services" for seriously emotionally handicapped children and adolescents, then substantial collaboration with other child caring systems may be possible. But first CASSP will need a new mental framework or paradigm to replace the traditional conception of mental health services for this population. This brings us to the third question or issue that CASSP must address.

What constitutes "rehabilitation" for children considered "seriously emotionally disturbed"?

CASSP has not addressed this issue explicitly, only indirectly through its goal of improving services for children and adolescents with serious emotional handicaps. But even in that context, CASSP is attempting "systems change" through its grants to individual states. Their objectives are admirable, but their strategies may only re-shuffle existing arrangements.

We think services can be improved to the extent that they have the goal of creating and sustaining systems of care that are environmentally based, functionally specific, advocacy oriented and family centered. This perspective is one that views the nature of rehabilitation as one of *care* rather than cure. It also shifts the locus of anticipated change from the intrapsychic arena to the child's environment.

While the goal of creating and sustaining a system of care for the emotionally handicapped child is a logical extension of more recent understandings regarding the nature of emotional disturbances in children as discussed above, it has practical consequences as well. A system of care approach organizes services around the child rather than vice-versa. It encompasses but does not require traditional notions of cure. And perhaps most importantly, it combines the resources of both natural and formal support networks.

The system of care approach, then, redefines mental health services by shifting the focus of intervention from the child's internal emotional state to the various behavior settings--home, school, work and play. In each setting, the "treatment issue" is the extent to which those in the setting understand and adjust to the child's disability by providing individualized instruction, support and reward. But as we have noted, for most seriously emotionally handicapped children, these various behavior settings are under the control of other systems of care.

What this means in practice will vary, of course, but the central issue is that it is the interactions between the child and each of the living, learning, play and work settings that bring mental health. Rehabilitation is the modification of each behavior setting to the point where the child can function at some level that is no longer perceived as disruptive. In concert these modified settings constitute a system of care in which the components may involve caseworkers, case managers, foster parents and family therapists from the child welfare system; probation officers, correctional counselors, recreational or occupational therapists and youth advocates from the juvenile justice system; teachers, guidance counselors and special education intructors from the educational system; and relatives, friends, neighbors and clergy from the child's natural sup-

port system. This brings us to the last issue for re-thinking.

What is the role of parents and professionals in programs of rehabilitation?

Historically, mental health professionals and other service providers have viewed parents as contributing to the cause of emotional disturbances in their children. That perspective viewed successful treatment as requiring either removal of the child from the parents' control and influence or treating them simultaneously, or both. More recent awareness of the iatrogenic effects of removing children from their parents for treatment, combined with the changes practitioners have seen families capable of making in response to various family therapy/training/education approaches, have led to a re-examination of our understanding of parents' roles in the origin and evolution of emotional disabilities in their children and of our assumptions regarding their proper role in programs of rehabilitation. Specifically, practitioners have noted that parents of children with special needs rarely receive the information they require to understand their children soon enough, but that when they do, they are frequently the most effective advocates for their children.

There is a growing awareness that most parents of emotionally handicapped children would be more willing to act as "case advocates" for their children, if only they could get the help they need being parents. The question is whether they can look to professionals for that help and get it.

The CASSP initiative is actively promoting the involvement of parents of emotionally handicapped children in states' efforts to plan improvements in services for emotionally handicapped children. But ultimately it would seem necessary to promote professionals' involvement in helping the parents as parents. It seems doubly unfair to expect parents to struggle first with parenting their own handicapped child and then to advocate for improvements in services for other parents' children. It seems both more fair and more reasonable for professionals to collaborate with parents in both roles and their respective tasks. The system of care approach put forth here would provide a natural opportunity for both parents and professionals to work with and learn from each other. Both could share the burden of parenting and creating a system of care that combines formal and natural support networks on the individual "case" level. And perhaps both could share the burden of attempting advocacy at the "systems" level and sustain each other during the inevitable frustrations and disappointments these efforts entail.

Beyond the issues of advocacy and parent/professional collaboration, the system of care approach views family-oriented efforts as essential to improving services for this population. Every child deserves to have a viable family and this is no less true for emotionally handicapped children. In the system of care approach, since children with special needs require special environments, the child's natural family may *not* have the special resources to accommodate the child's disability. A specialized or therapeutic foster family home may be the special home environment needed. But this does not mean that the child's natural family should be excluded from the system of care. On the contrary, the system of care approach implies that while "home" and "family" need not be synonymous, both are desirable for sustaining an ongoing system of care.

In summary, for the CASSP initiative to succeed, it must de-mystify "emotional disturbances" in children by defining impaired emotional functioning in terms of specific living, learning, working and playing contexts; initiate collaboration with other child caring systems in the creation and maintenance of systems of care for each child; and reform professionals' attitudes and behaviors regarding parents of emotionally handicapped children.

Tom Young is an assistant professor of social work at Portand State University. He specializes in direct human services to children, youth and families. Dr. Young served as director of the Research and Training Center during its first two years of operation.

REVIEW

THE NEW YORK LONGITUDINAL STUDY

The following is a review of the New York Longitudinal Study, a study of behavior disorders in children. The results of the study were authored by Stella Chess, M.D., and Alexander Thomas, M.D., first in "Genesis and Evolution of Behavioral Disorders: From Infancy to Early Adult Life"[1] , and subsequently in *Origins and Evolution of Behavior Disorders: From Infancy to Early Adult Life*[2].

The Study

The study, begun in 1956, followed 133 subjects from early childhood to early adulthood. The focus of the study was to identify and characterize temperamental characteristics and to study their influence on normal and deviant psychological development. Data sources included parent and teacher interviews, school and behavioral observations, clinical evaluations, and direct interviews with the subjects in adolescence and early adulthood.

Temperament was measured in nine categories in terms of the child's activity level, regularity in biological functions, response to new stimuli, adaptability, threshold of response, intensity of reaction, quality of mood, distractability and attention span.

Within these categories three "temperamental constellations" were defined: the "easy" child, the "difficult" child and the "slow-to-warm-up" child. The easy child was characterized by regularity, positive approaches to new stimuli, high adaptability to change, and mild to moderate mood intensity which is generally positive. The difficult child is characterized by irregularity, negative withdrawal responses to new stimuli, non- or slow adaptability to change, and intense mood expressions which are frequently negative. The slow-to-warm-up child is characterized by negative responses of mild intensity to new stimuli, to which the child would slowly adapt given repeated contact, less tendency toward irregularity, and mild intensity of reactions.

The following are some of the results of the study:

1. significant correlations were found between:
   - easy-difficult temperament at age three and temperament in early adult life
   - easy-difficult temperament at age three and adjustment in early adult life
   - parental conflict at age three and early adult adjustment in a negative direction
   - adjustment at ages three and five and adjustment in early adult life
   - clinical case status in childhood (e.g., adjustment disorder) and in early adult life
   - clinical case status in childhood and early adult adjustment in a negative direction
2. separation, divorce or death of a parent was not predictive of early adult status
3. there were no consistent correlations based on sex of the child
4. childhood factors which correlated with a high risk for relatively poor overall adjustment and/or presence of a psychiatric disorder in early adult life included: difficult temperament, parental conflict and presence of a behavior disorder.

These conclusions account for 34% of the subjects. The authors explain that the differences in outcome for the remaining 66% may lie in either variables not rated in the study or in differences in the sequences in which individual subjects developed psychologically.

Theoretical Implications

In cases where behavior disorders developed in later childhood and adolescence, a review of early childhood data did not show symptoms of conflict and stress that may have led to the disorder. In view of

Continued on page 12

Research and Training Center
PUBLICATIONS

$5.00

☐ *National Directory of Organizations Serving Parents of Seriously Emotionally Handicapped Children and Youth*
The U.S. organizations included provide one or more of the following services: education and information; parent training; case and systems level advocacy; support groups; direct assistance such as respite care, transportation and child care.

FREE (one copy per address, please)

☐ *Child Advocacy Annotated Bibliography*
Includes selected articles, books, anthology entries and conference papers written since 1970, presented in a manner useful to readers who do not have access to the cited sources.

☐ *Annotated Bibliography. Parents of Emotionally Handicapped Children: Needs, Resources, and Relationships with Professionals*
Covers relationships between professionals and parents, parent self-help, support and advocacy groups, parent participation, parents' problems and guidelines.

☐ *Annotated Bibliography. Youth in Transition: Resources for Program Development and Direct Service Intervention*
Transition needs of adolescents: educational and vocational issues, programs and curriculum, research overviews, interpersonal issues, skills training.

☐ *Families as Allies Conference Proceedings: Parent-Professional Collaboration Toward Improving Services for Seriously Emotionally Handicapped Children and Their Families*
Held in April 1986 and attended by delegations from thirteen western states. Includes: agenda, presentation transcriptions, biographical sketches, recommendations, worksheets, and evaluations.

☐ *Gathering and Sharing: An Exploratory Study of Service Delivery to Emotionally Handicapped Indian Children*
Findings from Idaho, Oregon and Washington, covering current services, successes, service delivery barriers, exemplary programs and innovations.

Checks payable to: Regional Research Institute
Mail order to: Research and Training Center, Regional Research Institute, Portland State University, P.O. Box 751, Portland, Oregon, 97207, (503) 229-4040

Research and Training Center
ORDER FORM AND MAILING LIST

☐ Please send me the publications indicated above. $_____ enclosed as appropriate.

☐ Add me to your mailing list. ☐ Take me off your mailing list.

☐ Change my address as noted below.

☐ List my organization in the national directory. (The Research and Training Center will contact you.)

NAME _____

ORGANIZATION _____

CITY/STATE/ZIP _____

TELEPHONE _____

CHECKS PAYABLE TO: Regional Research Institute
MAIL TO: Resource Services Coordinator, Research and Training Center, Regional Research Institute, Portland State University, P.O. Box 751, Portland, Oregon 97207, (503) 229-4040

Continued from page 10

this, the authors question Freud's theory that neuroses are acquired only during early childhood.

The data do not support the theory that anxiety plays a primary role in the development of behavior disorders. Anxiety appeared to be a consequence rather than a cause of behavior disorders.

The concepts of goodness/poorness of fit and consonance and dissonance were useful in tracing individual developmental sequences. The authors conclude that "excessive stress resulting from poorness of fit between environmental expectations and demands and the capacities of the child at a particular level of development...leads to disturbed behavioral functioning" (Thomas,1984a).

Practical Implications

"Parent guidance" was used to improve the goodness of fit for childhood clinical cases. The emphasis of parent guidance is to effect a change in the behaviors and overtly expressed attitudes of the parents as well as altering other unfavorable environmental influences. This technique generally required only a few sessions and was found to be quite effective in the majority of cases. With few exceptions, the recovery lasted throughout adolescence and early adult life.

The study offers a hopeful view of human development. Emotionally handicapped children can be helped. Family patterns and behavior can be refashioned and preventitive and theraputic interventions can produce change among all age groups.

References

1. Thomas, A. and Chess, S. (1984). Genesis and evolution of behavioral disorders: From infancy to early adult life. Reprint from *American Journal of Psychiatry*, 141 (1), 1-9.
2. Chess, S. and Thomas, A. (1984). *Origins and Evolution of Behavior Disorders: From Infancy to Adult Life*. New York: Bruner/Mazel, Inc.

Research and Training Center
Regional Research Institute
Portland State University
P.O. Box 751
Portland, OR 97207

Nonprofit Org.
U.S. Postage
PAID
Portland, OR
Permit #770

WINTER 1987

FOCAL POINT™

Families as Allies Conference

The Families as Allies Conference was held in Portland, Oregon, on April 28 and 29, 1986. The mission of the conference was to promote collaborative working relationships between professionals and parents of seriously emotionally handicapped children and adolescents. Designed as a working conference, parents and professionals from thirteen western states were invited to attend. Representatives from the following states participated: Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington and Wyoming.

While the composition of each state delegation varied, the goal was to assemble state delegations composed of:

(1) policy-making, administrative and service delivery professionals from the major public systems that serve emotionally handicapped children and youth, i.e., mental health, child welfare, juvenile justice, education and vocational rehabilitation;
(2) private service providers; and
(3) parents of emotionally handicapped children and adolescents.

Each delegation was encouraged to meet prior to the conference.

The keynote address was given by Susan DeConcini. Ms. DeConcini is a practicing social worker in the mental health field and is a child care advocate. The keynote speaker's theme of mutual respect helped set the tone for parent-professional collaboration and for much of the work that occurred during the rest of the conference. She noted, "It really is a partnership--a joining of hands together so that everybody wins." Parents of emotionally handicapped children are desperate for information about emotional problems and are eager to learn coping skills. Open communication between parents and professionals is essential. Subsequent speakers, panelists, and workshop leaders provided conference participants with both thought-provoking commentary and with ideas they could adapt to their own circumstances.

Obstacles to parent-professional collaboration were explored during the first day of the conference. Theories of etiology of mental illness often unwittingly cast parents as villains and are a serious obstacle to parent-professional collaboration. These beliefs lead to professionals blaming parents, holding them responsible and viewing them as pathogenic agents. Similarly, parents often also believe they are to blame for their children's problems. This belief may lead to guilt, shame, fear and avoidance of mental health professionals, teachers, and others.

Professionals tend to view children's needs and problems from within the context and capacities of the agency in which they are employed and within a relatively short time frame.

Continued on page 3

Keynote speaker Susan DeConcini. (Photo by Tom Young.)

The Bulletin of the Research and Training Center
to Improve Services for Seriously Emotionally Handicapped Children and Their Families

VOLUME 1 NUMBER 2

FROM THE EDITOR

This issue of *Focal Point* features the Families as Allies Project, which is designed to promote collaboration between families of children with emotional handicaps and the professionals who serve them. Project objectives include conducting relevant research, developing training curricula and other written materials, and designing and presenting workshops and other training events.

Included in this issue is a report about an April, 1986 conference held in Portland that involved equal numbers of parents and professionals from thirteen western states. This meeting was one of the first public explorations of our project concepts, and we were very gratified by the positive response of most participants.

As a part of our research program, we are currently conducting a survey in which we ask parents about their experiences seeking and obtaining services for their children. We are also involved in a search for innovative programs and faculty within professional schools that encourage professionals to work collaboratively with parents.

Curriculum development activities of the Families as Allies Project are also featured. Among these, we are happy to announce the availability of training materials developed by two parent organizations through an agreement with the Research and Training Center.

Because one purpose of *Focal Point* is to provide a forum for various points of view about important issues regarding children and their families, we are pleased to include an essay by Ira Lourie, M.D. and Judith Katz-Leavy, M. Ed., of the Child and Adolescent Service System Program (CASSP) Branch at the National Institute of Mental Health (NIMH). The essay constitutes a response to an article by Thomas Young, Ph.D., published in our last issue entitled, "Re-Thinking Emotional Disturbance." We hope that other readers will be stimulated to express their ideas regarding these and other important issues related to the mental health needs of children and their families.

RESEARCH AND TRAINING CENTER
Regional Research Institute for Human Services
Portland State University
P.O. Box 751
Portland, Oregon 97207
(503) 229-4040

Copyright © 1987 By Regional Research Institute for Human Services. All rights reserved.

We invite our audience to submit letters and comments.

RESEARCH AND TRAINING CENTER
Barbara J. Friesen, Ph.D., Director

Families as Allies Project
Barbara J. Friesen, Ph.D., Principal Investigator

Therapeutic Case Advocacy Project
Thomas M. Young, Ph.D., Principal Investigator
James L. Mason, B.S., Project Manager

Youth in Transition Project
Matthew J. Modrcin, Ph.D., Principal Investigator

Resource Services
Marilyn C. McManus, J.D., Coordinator

Focal Point
Marilyn C. McManus, J.D., Editor

Center Associates
Terry E. Butler, B.A.
Paul E. Koren, Ph.D.
Loretta Norman, B.A.
Douglas C. Overlock, B.A.
A. Christina Rutland, B.S.
E. Darey Shell, B.S.
Janis K. Worthington
Katie S. Yoakum, B.S.

GRADUATE SCHOOL OF SOCIAL WORK
Bernard Ross, Ph.D., Dean

REGIONAL RESEARCH INSTITUTE FOR HUMAN SERVICES
Arthur C. Emlen, Ph.D., Director

NATIONAL ADVISORY COMMITTEE

Mary Hoyt, M.S.W., Chair, Oregon State Hospital, Child and Adolescent Unit

Richard Angell, M.D., Department of Psychiatry, Oregon Health Sciences University

William Anthony, Ph.D., Center for Rehabilitation Research and Training in Mental Health, Boston University

William Arroyo, M.D., Assistant Director, Child/Adolescent Psychiatry, Los Angeles County—USC Medical Center

Marva Benjamin, M.S.W., Elahan Community Mental Health Center, Vancouver, Washington

Betsy Burke, Ph.D., Chief, Special Populations, California State Department of Mental Health

Lee Clark, Ph.D., Emotionally Handicapped Programs, Bureau of Education for Exceptional Students, Florida Department of Education

Glenda Fine, Parents Involved Network, Mental Health Association of Southeast Pennsylvania

Bud Fredericks, Ed.D., Teaching Research, Inc., Western Oregon State College

Paula Goldberg, PACER Center, Inc., Minneapolis, Minnesota

Mareasa Isaacs, Ph.D., Associate Commissioner for Children and Youth, New York Office of Mental Health

Phyllis Magrab, Ph.D., Director, Child Development Center, Georgetown University

Barbara Melton, B.S., Monmouth, Oregon

Larry Platt, M.D., Office of the Regional Health Administration, U.S. Public Health Services, Region IX

Ann Turnbull, Ph.D., Bureau of Child Research, The University of Kansas

CONFERENCE continued from page 1

Parents, on the other hand, have an ability to see the many needs of the child and the family, and thus the need for a wide range of services over a longer time span. Parents, however, may lack the knowledge and skills to put together a long term comprehensive plan unassisted.

Professionals and parents are further constrained by the requirement that professionals operate within agency policy and within the limitations imposed by funding sources. Agency policies and funding requirements are often impediments to the delivery of appropriate services to emotionally handicapped children.

The second day of the conference was devoted to developing strategies to overcome barriers to parent-professional collaboration. Panelists emphasized the importance of parent empowerment, the necessity for professionals to examine their attitudes toward parents and to view them as equals, and the value of parents' equipping themselves with the knowledge and skills needed to function as equal partners. One presenter urged that we re-examine the theories about the causes of emotional disturbance that lead us to blame parents.

Additionally, a multicultural project that trains parents to serve as trainers and that assists parents to assume leadership roles, as well as a project to develop parent support groups and services for military families were presented by panel members.

Following the presentations, members of state delegations met together to develop action plans and strategies for implementation upon return to their home states. Planned activities include efforts to better coordinate the activities of existing statewide advocacy groups, commitments to establish parent support groups in specific cities or regions, development of resource directories, establishment of parents-training-parents capabilities, development of parent handbooks, publishing newsletters, and engaging in legislative advocacy.

Nationally, four regional Families as Allies conferences have been scheduled. For more information, contact the following:

GREAT LAKES/APPALACHIAN REGIONAL CONFERENCE
Illinois, Indiana, Kentucky, Michigan, Minnesota, Ohio, Tennessee, West Virginia, Wisconsin
June 27 and 28, 1987
Bloomington, Indiana
Jim Killen (317) 232-7888 [IN]
Dagmar Plenk (608) 266-2712 [WI]
William Scott (502) 564-7610 [KY]
Donna Simonson (217) 785-2561 [IL]

MIDWEST REGIONAL CONFERENCE
Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma, South Dakota, Texas
May 13 and 14, 1987
Overland Park, Kansas
Rock Richardson (405) 521-0044 [OK]
(Arkansas, Oklahoma, Texas)
Art Sands (913) 296-3774 [KS]
Kansas, Missouri, North Dakota)
Jose Soto (402) 471-2851 [NE]
(Iowa, Nebraska, South Dakota)

NORTHEAST REGIONAL CONFERENCE
Connecticut, Delaware, Maine, Massachusestts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, Vermont, Virgin Islands
May 20 and 21, 1987
Albany, New York
Mary Armstrong (518) 474-8394 [NY]
Lenore Stern (717) 783-8335 [PA]
Joyce Wale (609) 987-2005 [NJ]

SOUTHEAST REGIONAL CONFERENCE
Alabama, District of Columbia, Florida, Georgia, Louisiana, Maryland, Mississippi, North Carolina, South Carolina, Virginia
June 12 and 13, 1987
Mobile, Alabama
Donna Glass (205) 271-9261 [AL]
Lucy Leslie (601) 359-1301 [MS]

Panelists Glenda Fine, Richard Donner and Cindy Boatman. Topic: Obstacles to Parent-Professional Collaboration. (Photo by Tom Young.)

Update of States Involved in the Families as Allies Conference

Alaska - Post-conference activities in Alaska have addressed two areas:

(1) parent involvement and support at a residential treatment facility; and
(2) governmental lobbying efforts.

A bi-weekly parent support group has been established at a residential treatment facility in Juneau. Parents of children served by this residential treatment facility will serve on the agency's board of directors on an ongoing basis. One member of the Alaska delegation has met with the state's CASSP project manager on several occasions, and has worked with legislators on an upcoming bill to establish an Alaskan children's trust fund, and also met with many candidates prior to the November election to discuss issues affecting children and youth.

Arizona - Members of the Arizona delegation have not met on a formal basis. The coordinator of the Arizona delegation did, however, meet with the state hospital's youth coordinator and discussed the goals of the Families as Allies Conference. The governor's representative on children, youth and families, as well as other gubernatorial staff members, will be included in future efforts to improve parent and professional collaboration.

California - California was unable to send a formal delegation to the Portland conference because of scheduling conflicts. The relevant professionals in the state were meeting at the same time as our conference to work on issues of interagency collaboration in delivering services to emotionally handicapped children and their families. This same group plans to meet again in the Spring of 1987, at which time the issues of parent-professional collaboration will be discussed. California has funded a demonstration project in Ventura County to develop a model of service delivery to seriously emotionally handicapped children and their families.

Colorado - The group representing Colorado at the conference has not met on a formal basis. However, the Department of Mental Health is initiating the planning meetings for a forum to be held in the Spring of 1987. The planners are seeking to identify people throughout the state who share an interest in advocacy efforts and children's issues. These individuals will be invited to attend the forum. The objectives are to:

(1) share information on advocacy efforts;
(2) identify children's and families' needs;
(3) identify obstacles to parent-professional collaboration;
(4) plan for establishment of a broad-based constituency; and,
(5) form task groups to work on establishing state and local advocacy groups.

Additionally, the Department of Mental Health is formulating plans to replicate the Families as Allies Conference for Colorado parents and professionals.

Hawaii - Hawaii is a CASSP state with a strong interagency network in place. The group attending the conference included an equal number of parents and professionals. This group continues to meet monthly and planned a December Hawaii Families as Allies Conference. The conference was modeled on the Portland effort, and encouraged participants to attend as parent-professional teams. In addition, the CASSP project has hired a Parent Coordinator, Ginny Wright.

Idaho - Idaho's CASSP staff has taken numerous steps to improve parent-professional collaboration within the state. These efforts include:

(1) the identification of parents of emotionally handicapped children;
(2) parent and professional participation in regional needs assessment surveys to identify the essential components of an Idaho treatment delivery system;
(3) coalition building meetings held in each of Idaho's seven regions with parents, mental health professionals, teachers and service providers;

(4) a statewide CASSP conference involving administrators, parents and professionals held in Sun Valley in October; and
(5) publication of the first two issues of a statewide newsletter. One page of each issue of the newsletter will be devoted to an editorial written by a parent or to the discussion of parent issues.

Montana - The Montana delegation to the Conference formed their own organization called Montana Families as Allies. Since Montana is a large state geographically, and each of the five parents were from different cities, the group has not been able to meet. However, the state coordinator is in communication with local coordinators to encourage local efforts, perhaps in conjunction with existing groups or organizations. The state coordinator (a parent) is the only consumer on a state task force charged with devising a legal definition of emotional disturbance for presentation to the state legislature. She has also written an article for the Montana Mental Health Association Newsletter.

Nevada - The members of the Nevada delegation disseminated a brief press release to key state and local professionals in which they described the Families as Allies Conference. The statement identified the lack of interagency coordination as the most pressing problem hampering the provision of services to the state's emotionally handicapped children. Delegation members have not formally met since the conference.

New Mexico - The New Mexico delegation has maintained contact with each other. They are working on two projects designed to help create a statewide network for parents. The first is the production of a videotape created by a parent group. The videotape will be used for outreach to parents living in rural areas of the state. The second project is the purchase of space in the New Mexico Alliance for the Mentally Ill newsletter dedicated to children's issues. Both projects are funded by the Mental Health Bureau.

Oregon - Three support groups for parents of children with emotional handicaps have started since the April conference. These groups are located in Portland, Lake Oswego, and Monmouth. The Monmouth group has named itself Families and Children Together (F.A.C.T.) and is seeking support from the Mental Health Association of Oregon. The Oregon Mental Health Division (OMHD) has recently named Faye Lindemann-Tayler as the Coordinator of Programs for Children and Adolescents. This appointment should increase the emphasis given to children's mental health issues in the state. This is the first time in many years that an OMHD position has been devoted exclusively to children's issues.

Utah - One member of the Utah delegation met with the state's Interagency Commission and thereafter arranged for the director of the Utah Parent Center to meet with the Commission. As a result of these meetings, agencies will now refer parents to the center. The center will serve as the focal information center and will direct parents to the appropriate resource.

Washington - A follow-up meeting to the Portland conference was held in the Fall of 1986. The action plan developed by the state delegation was updated and revised. The plan includes a statewide parent-professional conference in the second or third year of Washington's CASSP activities. The Washington CASSP staff is conducting ongoing discussions with established advocacy groups in the state to assist with their advocacy efforts and to develop strategies for working together. Three parents serve on the state's CASSP Coordinating Council. In addition to the experience and skill he brings to the position, the newly appointed assistant CASSP Project Director is the parent of a psychiatrically disabled child.

Wyoming - The Wyoming delegation has not met as a group. One member of the delegation, who has since moved out of the state, made a public presentation in which she discussed the conference.

A Perspective on Rehabilitative Services Within the Child and Adolescent Service System Program

by
Ira S. Laurie, M.D. & Judith Katz-Leavy, M.Ed.

In the lead article of the premier issue of *Focal Point*, Dr. Thomas Young challenges some of the basic concepts of the Child and Adolescent Service System Program (CASSP). Dr. Young feels that the terminology of "severely emotionally disturbed" children and adolescents will focus too strongly on the mental health aspects of the child's service needs and will lead to the development of a narrow system of care and a focus on behavior as perceived by parents and teachers. He does this in face of the reality that "severely emotionally disturbed" (SED) is an educational term that is not found in the mental health literature. This term has been adopted by CASSP as an alternative to the concept used in mental health to describe this population of chronically mentally ill children and adolescents. The national work group brought together to develop CASSP chose this definition in an attempt to demonstrate the need for a broad based continuum of care similar to the one that Dr. Young suggests is needed.

Dr. Young implies that only by adopting a rehabilitative model will CASSP be able to create the appropriate continuum of care. In the service of this conceptualization he states that the Portland R&T Center has changed its own terminology from "emotionally disturbed" to "emotionally handicapped," as he states, "because we believe it helps us shift our focus from the child-as-problem to the context-as-solution." On one hand, it seems that this is just a semantic quarrel which will not prove to be particularly useful to the field in the long run. On the other hand, Dr. Young urges a focus on "rehabilitation" which we feel may well prove detrimental to the promotion of developmentally focused corrective services.

The use of the term "severely emotionally disturbed children and adolescents" by CASSP comes from the same concerns addressed by Dr. Young. CASSP originally selected the term "seriously emotionally disturbed" (SED) to provide as much consistency as possible with the categories of eligibility used in the Education of the Handicapped Act, P.L. 94-142. This initial decision was indicative of CASSP's commitment to taking a total system-wide approach to service delivery and to our acknowledging that mental health services take many different forms and are provided in a variety of community-based settings by a broad range of agencies and providers.

In the 1983 Concept Paper on the Child Adolescent Service Systems Program prepared by Beth Stroul, in the CASSP grant guidelines published annually, and again in the July 1986 monograph, *A System of Care for Severely Emotionally Disturbed Children and Youth*, by Stroul and Friedman, CASSP presented a set of five basic parameters for defining the target population. The first parameter addressed age limitations, and was immediately followed by the following two parameters:

- "The target population should include children whose emotional problems are disabling based upon social functioning criteria. Level of functioning is a critical variable for children and adolescents, determining the nature and level of care that is appropriate. Degree of disability or level of functioning in family, school and community contexts is often more meaningful than mental health diagnosis in planning and delivering services."
- "Children and adolescents included in the target population should have a multiagency need. Severely emotionally disturbed youngsters require a range of services which necessitates the involvement of multiple agencies including mental health, health, education, child welfare, juvenile justice, and others."

Dr. Young proposes a system-wide approach to service delivery which emanates exclusively from the rehabilitation model. We, at CASSP, feel very strongly that it should not. We contend that there are specific problems in apply-

ing the rehabilitation model to severely emotionally disturbed children and adolescents which should not go unaddressed. Rehabilitation is a concept that has traditionally applied to adults and physically handicapped children. In discussing the World Health Organization's perspective on disabilities, Dr. Young states that the Portland R&T Center is "concentrating on research and training activities designed to help parents, teachers, employers and the helping professions find ways of modifying living, learning and working environments to accommodate, adjust to and compensate for children with emotional disabilities." Further, he refers to "modifying environments so that children are no longer handicapped by their emotional disabilities in those contexts." Dr. Young appears to view the disabilities of these youngsters as static, disregarding the concepts of growth and development as well as the possibility of corrective change.

While rehabilitation, as used in the context of the Portland R&T Center, should be a vital component of any service system, a total focus in that area will necessarily deny appropriate options to those children and adolescents who have the capacity to decrease their disabilities through growth and psychological therapy. Our view of intervention with severely emotionally disturbed/handicapped children and adolescents is based on the concept of habilitation or positive change. Orthopsychiatry describes the process of corrective intervention. This has been the traditional rallying point for child mental health professionals, special educators, juvenile justice specialists and child welfare workers for years, and there is no indication that we should give up on it now.

While rehabilitation, as discussed by Dr. Young, serves an important role in the services system defined by CASSP, the practice of current rehabilitation agencies has not been child and adolescent oriented to this time. For rehabilitation to take its proper role, there must be adjustments in how these principles are applied to children. This is especially true in regard to how the needs of adolescents are met as they progress from the child to the adult service systems.

Whether we refer to disabled children as "disturbed" or "handicapped" will not deter our joint efforts to provide the most appropriate intervention along a continuum of care that includes corrective therapies as well as rehabilitative solutions.

Dr Lourie is the Assistant Chief of the Community Service Systems Branch of the National Institute of Mental Health. Ms. Katz-Leavy is the Program Director of the Child and Adolescent Service System Program of the National Institute of Mental Health.

Parent Organization Survey

From July, 1985, to February, 1986, a national survey was conducted of organizations for parents of children with serious emotional handicaps. This telephone survey was carried out by regional centers of the Technical Assistance for Parents Program (TAPP) and by staff of the Research and Training Center. We gathered information about the history of the parent groups, the activities and services provided by them, their views of the current service delivery system, and their plans for the future. An immediate practical use of the information gathered was to publish a national directory of parent organizations which is available through our Resource Center.

Some highlights of the findings include:

207 (100%) **parent organizations** in 47 states were **included in the survey**. No parent groups were found in Iowa, Missouri and Wyoming.

60 (29%) of the organizations **have an exclusive focus on emotional disturbance** and do not serve or include other disabilities. Many of the remaining organizations developed in response to P.L. 94-142 and serve families representing a wide range of childhood disabilities.

205 (99%) **provide education/information services** to parents. Of these, more than three-quarters provide specific information about emotional

disturbance and the rights of children and families under P.L. 94-142.

184 (89%) **provide parent training** in such areas as coping with the needs of emotionally handicapped children and developing effective case and systems advocacy skills.

177 (86%) **engage in advocacy activities.**

131 (63%) **sponsor support groups** that are available to parents of emotionally handicapped children and adolescents. Only 52 organizations (25%) provided support groups exclusively for parents of this population.

164 (79%) **provide** some type of **direct assistance to parents.** These services include assistance in dealing with agencies or the public schools, child care, transportation, respite care, assistance with food, money or shelter, and homemaker services.

196 (95%) **provide training or other services for professionals.** Most frequently mentioned were information designed to help professionals understand the needs of families and services aimed at improving the working relationship between family members and professionals.

Asked about future plans, respondents identified the following areas as those in which they would like to expand (as one of three choices):

Education/information for parents	109
Skills training	102
Advocacy	84
Support groups	70
Services to improve parent-professional relationships	63
Direct assistance	61
Other services to professionals	29
Counseling for parents	25

Respondents were also asked about a number of service delivery system issues. Three issues identified by a majority of respondents as extremely important were:

There are not enough services for all children who need them;

Low income or lack of insurance prevents families from obtaining services; and

Services are not available to children and families regardless of location, i.e., geographical barriers and maldistribution of services create an uneven system of care for this population.

A full report of the findings of the Parent Organization Survey is available through the Resource Center.

Parent Produced Training Materials

The Families as Allies Project has funded two parent organizations to produce training materials designed to promote parent-professional collaboration. Using videotape and a workbook format, each product takes an informative, educational approach.

The PACER (Parent Advocacy Coalition for Educational Rights) Center in Minneapolis, Minnesota has produced a professional quality videotape entitled *Parent's Voices: A Few Speak for Many.* Intended for viewing by professionals, the tape features a narrator and three parents (all of whom have children with diagnosed emotional handicaps) discussing the experiences they have had seeking help for their children. The parents discuss their feelings of frustration in their efforts to communicate with helping professionals and their belief that they are often left out of the treatment process. They describe how poor coordination between agencies, as well as the differing perspectives of schools and various treatment workers, added to the problems they were already experiencing. Although the program is designed with a professional audience in mind, it should also be useful for groups composed of parents or other interested persons.

PLUK (Parents, Let's Unite for Kids), affiliated with the Montana Center for Handicapped Children, has drafted *Parent Information Workbook on Emotional Handicaps.* Designed as a self-teaching workbook for parents, it covers a

range of topics and seeks to increase parents' awareness and decision-making capabilities on important issues. One section, "Being the Parent of an Emotionally Disturbed Child," discusses thoughts and feelings parents often must face about themselves, their children, and the people around them. Many of the comments come from parents who have children with emotional handicaps. Also included are information on various diagnoses, types of professionals and treatments, and legal aspects of the treatment and special education systems.

PLUK has also produced two complete workshop formats in the areas of parent-professional collaboration and systems advocacy. The first workshop, *Working Together: The Parent Professional/Partnership*, includes activities designed to increase the understanding professionals and parent's have for each other's feelings, needs and limitations, an examination of roles, and strategies to promote cooperation. *Making the System Work: An Advocacy Workshop for Parents*, addresses topics such as the importance of advocacy, power and problem-solving techniques and strategies for making effective demands. Each set of materials includes a guide for trainers, copies of exercises, handouts and workshop evaluation forms. The materials are designed to provide a complete set of information and materials needed for a day long workshop in each area. Topical modules from each workshop can also be adapted for shorter training sessions, when needed.

These four new products should help enhance understanding and cooperation between parents of seriously emotionally handicapped children and the professionals working to help them. Information about the workshop materials can be obtained from the Resource Service.

NOTES & COMMENTS

SEARCH FOR INNOVATIVE PROGRAMS. CAN YOU HELP?

We are in the process of identifying innovative programs and materials designed to help professionals learn to work collaboratively with families of emotionally handicapped children. Many professional training programs focus on families as the target for change (placing family members in the role of patient) or stress the provision of services to family members (placing families in the client role). Our focus in this search is on programs that feature the role of parents as partners, or allies in the process of assessment, planning, implementation and evaluation of services. We want to identify programs and approaches that can be shared with faculty members in professional schools, and with professional organizations, parent groups, and other interested individuals and organizations.

Some interesting programs we have unearthed so far include a child psychiatry training program that uses parents as guest lecturers; several parent-professional workshops that use role play and role reversal to increase the empathy of parents and professionals for each others' perspective; and a number of written materials that re-examine or re-interpret traditional ways of thinking about families.

While we are most interested in programs and materials pertaining specifically to parents of children with emotional problems, we know considerable development has occurred in relation to groups such as adults with long term psychiatric disabilities, or children with conditions such as mental retardation or developmental disabilities, chronic health problems, autism, or learning disabilities. We welcome information from any quarter that will help us promote professional training that includes a broad definition of "help" for families, and encourages future professionals to work with family members in collaborative ways.

If you know of programs, materials, or people we should know about, please let us know. Thanks for your help!

NIHR NAME CHANGE

As of October 21, 1986, the National Institute for Handicapped Research (NIHR) changed its name to the National Institute on Disability and Rehabilitation Research (NIDRR). NIDRR and the National Institute of Mental Health (NIMH) are the two funding sources for the Portland Research and Training Center.

PARENT-PROFESSIONAL TRAINING PROGRAM LAUNCHED

A program to prepare parent-professional teams to provide training to help other parents and professionals learn to work effectively together will begin Spring, 1987. Through a contract with the Georgetown CASSP Technical Assistance Center, the Families as Allies Project will prepare curriculum materials and provide training to participants from throughout the country.

The trainees will be parents and professionals identified through the regional Families as Allies Conferences scheduled for May and June, 1987. During an initial week of intensive training in Portland, participants will increase their training skills as well as learn to present specific content related to parent-professional relationships, parent support groups, and advocacy strategies.

When they return to their own states and communities, the parent-professional training teams will be available to conduct workshops, provide consultation, and to teach others interested in becoming trainers. They will also assist in following the progress of the state delegations as they work to implement the state action plans developed during the Families as Allies Conferences.

HAWAII FAMILIES AS ALLIES CONFERENCE

On December 6, 1986 the Hawaii Families as Allies Conference was held in Honolulu. Approximately 130 parents and professionals worked productively together, and accomplished a great deal in the short time available. The conference was instrumental in increasing the awareness of public officials and the public-at-large. Portions of the general session were televised by the local CBS affiliate later that evening with an estimated viewing audience of over 42,000. An assistant to Hawaii's new governor, John Waihee, attended most of the conference and participated in a small group session that was very active in identifying issues and needs. Conference participants drafted a letter to the governor requesting a meeting with a delegation of parents and professionals.

Pursuant to their request, the Governor's Administrative Director met with conference representatives in January. The delegation was composed of representatives from the CASSP office, the Mental Health Association, the state Children's Mental Health Services Branch and two parents. The conference representatives urged the recognition of children's mental health as a state priority, discussed the need for a continuum of care and offered themselves and their agencies as resources to the Governor's office.

The conference was sponsored by Hawaii CASSP, the Mental Health Association in Hawaii, the Office of United Self Help and the Children's Mental Health Services Branch of the Mental Health Division of the Department of Health. Conference planners and participants met with great success. The conference served to stimulate increased activity on behalf of children and families in Hawaii, and shows every sign of being politically effective as well.

NAMI CONFERENCE TO FEATURE PARENT-PROFESSIONAL COLLABORATION

Parents and Professionals: Partners for a Change is the title of a meeting scheduled for September 15-17, 1987 in conjunction with the 1987 convention of the National Alliance for the Mentally Ill (NAMI). At present, there is hope that parent scholarship funding may become available through state CASSP offices. The meeting, which will focus on families of children and adolescents, will be held at the Washington Hilton in Washington, D.C. For more information, call NAMI at (703) 524-7600, or write to them at 1901 North Fort Meyer Drive, Suite 500, Arlington, VA 22209.

PARENT SURVEY

The Families as Allies Project plans to survey parents of children with serious emotional handicaps. The purpose of the survey is to identify parental concerns about services needed and received, about interactions with service providers, and about the helpfulness of various sources of formal and informal support. The results of the survey will be used to develop information and training materials to promote parent-professional collaboration. Although the questionnaire will be completed by parents, the cooperation of state and local organizations will be very important to reaching a cross-section of parents. When feasible, the use of a group setting for administration of the survey instrument

Continued on page 12

Research and Training Center
RESOURCE MATERIALS

☐ *Annotated Bibliography. Parents of Emotionally Handicapped Children: Needs, Resources, and Relationships with Professionals* *
Covers relationships between professionals and parents, parent self-help, support and advocacy groups, parent participation, parents' problems and guidelines.

☐ *Annotated Bibliography. Youth in Transition: Resources for Program Development and Direct Service Intervention**
Transition needs of adolescents: educational and vocational issues, programs and curriculum, research overviews, interpersonal issues, skills training.

☐ *Child Advocacy Annotated Bibliography*
Includes selected articles, books, anthology entries and conference papers written since 1970, presented in a manner useful to readers who do not have access to the cited sources. $7.00 per copy.

☐ *Families as Allies Conference Proceedings: Parent-Professional Collaboration Toward Improving Services for Seriously Emotionally Handicapped Children and Their Families**
Held in April 1986 and attended by delegations from thirteen western states. Includes: agenda, presentation transcriptions, biographical sketches, recommendations, worksheets, and evaluations.

☐ *Gathering and Sharing: An Exploratory Study of Service Delivery to Emotionally Handicapped Indian Children**
Findings from Idaho, Oregon, and Washington, covering current services, successes, service delivery barriers, exemplary programs and innovations.

☐ *National Directory of Organizations Serving Parents of Seriously Emotionally Handicapped Children and Youth*
The U.S. organizations included provide one or more of the following services: education and information; parent training; case and systems level advocacy; support groups; direct assistance such as respite care, transportation and child care. $5.00 per copy.

☐ *Parent Information Workbook on Emotional Handicaps*
This self-teaching workbook for parents addresses topics such as parents' feelings about themselves and their children, labels and diagnoses, types of professionals and treatments, and legal issues. Single copies free to parents of children with emotional handicaps while supplies last. All others, $3.00 per copy.

☐ *Parents' Voices: A Few Speak for Many* (videotape)
Three parents of children with emotional handicaps discuss their experiences related to seeking help for their children (45 minutes). Brochure describes videotape and provides purchase and rental information.

* One copy free per address while supplies last.

ORDER FORM AND MAILING LIST Research and Training Center

☐ Please send me the publications indicated above. $_____ enclosed as appropriate.

☐ Add me to your mailing list. ☐ Take me off your mailing list.

☐ Change my address as noted below.

☐ List my organization in the national directory. (The Research and Training Center will contact you.)

NAME _____

ORGANIZATION _____

STREET ADDRESS _____

CITY/STATE/ZIP _____

TELEPHONE _____

CHECKS PAYABLE TO: Regional Research Institute for Human Services
MAIL TO: Resource Services Coordinator, Research and Training Center, Regional Research Institute for Human Services, Portland State University, P.O. Box 751, Portland, Oregon 97207, (503) 229-4040

SURVEY continued from page 10

will facilitate completion of the questionnaire as well as provide help to parents in interpreting the questions. In addition to using the survey results for training curriculum development, the results may augment needs assessment information related to services for seriously emotionally handicapped children in individual states. Parents willing to participate in this survey should contact us directly by writing the Families as Allies Project. Your help will be appreciated.

OFFICE BURGLARY

Our offices were burglarized over the holidays. Five computers were stolen. One computer contained the *Focal Point* mailing list on its hard disk. Fortunately, the bulk of the list was backed up; however, some later changes to the list were lost. We have reconstructed the list to the best of our ability, but some information (such as changes in address) may have been lost. Please bear with us and send any address or personnel changes to us again. We apologize for the inconvenience.

FOCUS: THERAPEUTIC CASE ADVOCACY

The Therapeutic Case Advocacy Project is developing a model to deliver services to seriously emotionally handicapped youth and their families. The model coordinates the efforts of youth serving systems, organizations and agencies as well as the informal supports in the client's environment. Client centered systems of care are established through case advocacy, interpersonal interventions and care management. Collaboration at the case, organizational and interagency levels is an integral aspect of the concept.

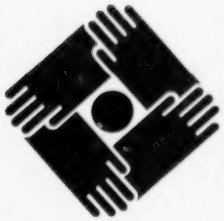
The next issue of *Focal Point* will feature the Therapeutic Case Advocacy Project. We are interested in hearing about similar models of interagency collaboration at the local level and would like to highlight them in our next issue. If you know of programs or models with similar approaches, please notify: James L. Mason, Therapeutic Case Advocacy Project Manager.

PORTLAND STATE UNIVERSITY
Research and Training Center
Regional Research Institute for Human Services
P.O. Box 751
Portland, Oregon 97207

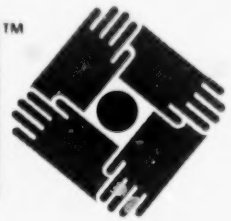
Nonprofit Org.
U.S. Postage
PAID
Portland, OR
Permit #770

RECEIVED OCT 0 8 1987

Spring/Summer 1987



FOCAL POINT™



Therapeutic Case Advocacy: A Summary

Therapeutic Case Advocacy (TCA) is one approach to helping emotionally handicapped children and their families. It is described here as a multi-level model to improve services for this population for two reasons. First, the approach typically requires planned, coordinated activity on three levels: the child and family, the lead organization providing services, and interagency collaboration. Second, the word "model" conveys the idea of what the real thing might look like.

The model is a preliminary pattern, a plan for guiding the actual process of helping emotionally handicapped children and their families. It is not a recipe. Any actual process of helping guided by this model may vary from that described here according to individual child and family need, organizational capacity, and community context. Nevertheless, there are three core components of this model for helping that, if adopted, would improve services for emotionally handicapped children and their families.

The first is the use of case advocacy to create an individualized system of care for each emotionally handicapped child and his or her family. The second is the use of a set of interpersonal interventions in order to engage the child and family in the process of designing, constructing and maintaining a system of care; persuade others in their organizations to approve and finance certain components of the system of care; and facilitate the interagency collaboration necessary to coordinate the activities of staff from two or more agencies and integrate them with the efforts of natural helpers in the family's personal community. The third is the application of care management skills to sustain the child and family and, selectively, both the formal and natural helpers contributing to the system of care.

The use of each component is guided by certain principles and requires certain skills listed below.

Component No. 1: Case Advocacy

Principles

1. The primary, over-arching goal is to create a system of care that surrounds and supports the child and family on a daily basis.
2. The "targets" of case advocacy efforts often are people too. Nothing is to be gained by declaring them enemies; advocacy can be partisan without being adversarial.
3. Child and family involvement in all aspects of the advocacy process is essential so that one end result of the advocacy is an enhanced capacity of children and their families to speak for themselves.

Skills: To Be Able To...

1. Identify "target areas" within an ideal system of care.
2. Define the resource development task for each behavior setting encompassed by the system of care.
3. For each behavior setting, locate who could provide alternative instruction, support, and reward for the child and/or family.
4. Acquire the history, if any, of previous interactions between child/family and potential providers.
5. Use the process of assessing the discrepancy between what child/family needs and what is currently provided to forge a personal relationship with the provider.

The Bulletin of the Research and Training Center
to Improve Services for Seriously Emotionally Handicapped Children and Their Families

VOLUME 1 NUMBER 3

6. Analyze the "price structure," in personal terms, for mobilizing the modified set of instruction, support, and reward desired in each behavior setting.
7. Specify the basis for having leverage in the situation.
8. Consider the effect of timing on the success of a request to provide (or allow provision of) alternative instruction, support and reward.
9. Formulate and prepare contingency plans in the event that the alternatives provided provoke a crisis between child/family and provider.
10. Propose, persuade, or entice potential provider to try alternative instruction, support, and reward.

Therapeutic Case Advocacy Project staff: (from left) Principal Investigator Tom Young, Project Manager James Mason, Center Associate Katie Yoakum. (Photos by Marilyn McManus.)

RESEARCH AND TRAINING CENTER

Regional Research Institute for Human Services
Portland State University
P.O. Box 751
Portland, Oregon 97207-0751
(503) 464-4040

Copyright © 1987 By Regional Research Institute for Human Services. All rights reserved.

We invite our audience to submit letters and comments.

RESEARCH AND TRAINING CENTER
Barbara J. Friesen, Ph.D., Director

Families as Allies Project
Barbara J. Friesen, Ph.D., Principal Investigator
Richard Vosler-Hunter, M.S.W., Training Coordinator

Therapeutic Case Advocacy Project
Thomas M. Young, Ph.D., Principal Investigator
James L. Mason, B.S., Project Manager

Youth in Transition Project
Matthew J. Modrcin, Ph.D., Principal Investigator

Resource Services
Marilyn C. McManus, J.D., M.S.W., Coordinator

Focal Point
Marilyn C. McManus, J.D., M.S.W., Editor

Center Associates
Patty Bundren
Terry E. Butler, B.A.
Steven Cooper, B.S.
Kaye Exo, M.S.
Paul E. Koren, Ph.D.
Loretta Norman, B.A.
A. Christina Rutland, M.S.W.
E. Darey Shell, B.S.
Katie S. Yoakum, B.S.

GRADUATE SCHOOL OF SOCIAL WORK
Bernard Ross, Ph.D., Dean

REGIONAL RESEARCH INSTITUTE FOR HUMAN SERVICES
Arthur C. Emlen, Ph.D., Director

NATIONAL ADVISORY COMMITTEE

Mary Hoyt, M.S.W., Chair, Oregon State Hospital, Child and Adolescent Unit

Richard Angell, M.D., Department of Psychiatry, Oregon Health Sciences University

William Anthony, Ph.D., Center for Rehabilitation Research and Training in Mental Health, Boston University

William Arroyo, M.D., Assistant Director, Child/Adolescent Psychiatry, Los Angeles County—USC Medical Center

Marva Benjamin, M.S.W., Elahan Community Mental Health Center, Vancouver, Washington

Betsy Burke, Ph.D., Chief, Special Populations, California State Department of Mental Health

Lee Clark, Ph.D., Emotionally Handicapped Programs, Bureau of Education for Exceptional Students, Florida Department of Education

Glenda Fine, Parents Involved Network, Mental Health Association of Southeast Pennsylvania

Bud Fredericks, Ed.D., Teaching Research, Inc., Western Oregon State College

Paula Goldberg, PACER Center, Inc., Minneapolis, Minnesota

Mareasa Isaacs, Ph.D., Associate Commissioner for Children and Youth, New York Office of Mental Health

Phyllis Magrab, Ph.D., Director, Child Development Center, Georgetown University

Barbara Melton, B.S., Monmouth, Oregon

Larry Platt, M.D., Office of the Regional Health Administration, U.S. Public Health Services, Region IX

Ann Turnbull, Ph.D., Bureau of Child Research, The University of Kansas

Component No. 2: Interpersonal Interventions

Principles

1. The primary, over-arching goal is to engage and sustain the child and family in the process of working out a new accommodation between them and their environment.
2. Interpersonal interventions are carried out in the service of case advocacy and management efforts to establish and maintain a system of care, not vice-versa.
3. The use of interpersonal interventions is not synonomous with providing psychotherapy. These skills are relevant to work with both the official client and with others in the client's environment.

Skills: The Ability To...

1. "Listen with a third ear" for things others would like to talk about but feel they cannot.
2. Absorb verbal abuse and aggression in response to the offer of help.
3. Understand and describe one's own feelings directly.
4. Acquire an empathic comprehension of another person's difficulties and convey that in both words and gestures.
5. Translate another person's psychological needs into plans for enhancing, restructuring, or otherwise modifying his/her environment's provision of instruction, support and reward.
6. Clarify one's own role and the purpose of the relationship, namely, to design and establish a system of care.
7. Break a larger problem or difficulty down into manageable but meaningful tasks to be pursued sequentially.
8. Encourage repeated feedback on both helpfulness of the relationship and the process of accomplishing tasks.
9. Anticipate the demands that new accommodations among children, parents, and their environments will make upon each other and devise opportunities for respite and reward as part of the process of constructing the system of care.
10. Set enforceable limits on the behavioral expression of anxiety, impatience, frustration, or anger and negotiate the consequences for when those limits are exceeded.

Component No. 3: Care Management

Principles

1. The primary over-arching goal is to coordinate, integrate and maintain a network of services that together with natural helping sources establish and support a functioning balance beween child, family and their environment.
2. The guiding idea behind care management is the routinization of an individualized system of care that remains flexible and adaptive over time as needs and circumstances change. Accountability, therefore, is ultimately to the child and family.
3. The process of care management is more important than its product. By definition, the process is individualized, interactive, and pluralistic.

Skills: The Ability To...

1. Assemble the people involved in each of the child/family's behavior settings to design the individualized system of care and each person's contribution (the TCA service team).
2. Involve the child and family in the process and verify mutual understandings and expectations.
3. Define goals for each component within the system of care against which accomplishments can be assessed at a future point in time.
4. Select a care manager from among the members of the TCA service team.
5. Review plans for modifying the provision of instruction, support, and reward in each behavior setting and establish a time/task chart that records who has planned to do what and by when.
6. Schedule meeting times and places for subsequent reviews and modifications of the planned provision of alternative instructions, supports, and rewards.
7. Establish measures of satisfaction with the system of care to be completed by the child, the parents, and each of the constituent members of the system of care.
8. Devise a system of 24-hour response capability for crisis intervention, preferably one that rotates responsibility among team members.

9. Create support systems for the providers in the system of care.
10. Formally evaluate the adequacy of the system of care from both the consumers' and providers' perspectives.

Assumptions

Two fundamental, and potentially controversial, assumptions of the model are that:

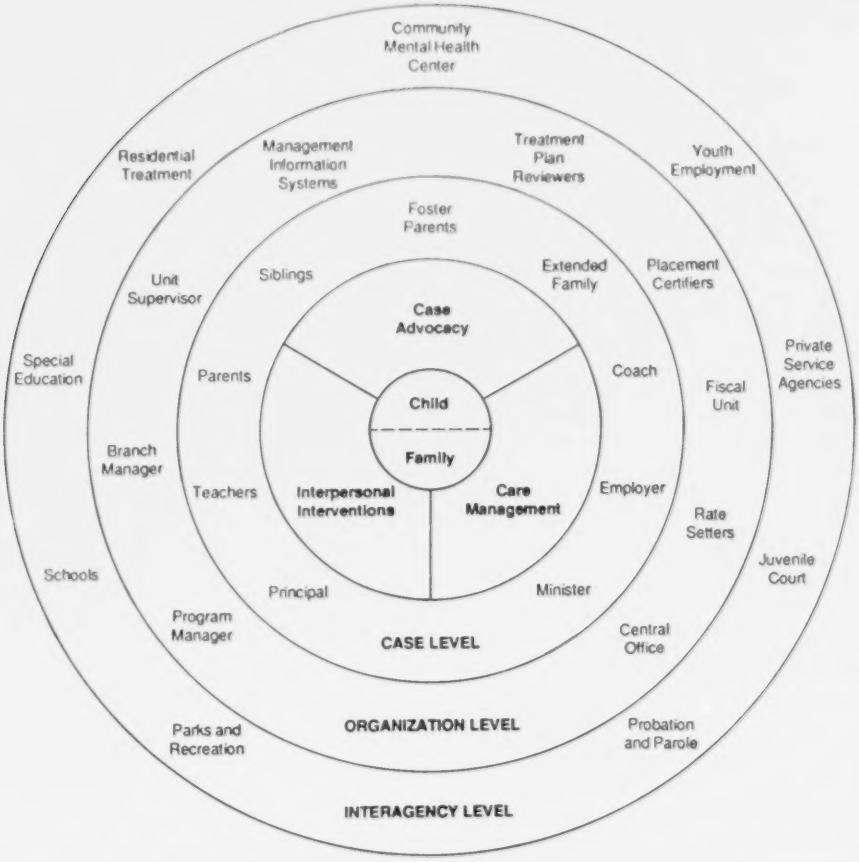
- emotional handicaps are affective and behavioral reactions to unmanageable discrepancies between what a child is capable of and what his or her environment expects and provides in the form of instruction, support, and reward; and

- to be effective, the system of care must include both services from formal organizations and help from natural support networks or personal communities.

The Role of Treatment

In attempting to construct and sustain individualized systems of care, Therapeutic Case Advocacy seeks to modify environments -- creating special environments for children with special needs. Therapy or mental health treatment is but one modification of a child and family's environment. What is therapeutic about Therapeutic Case Advocacy is the recalibration of expectations, instruction, support, and reward in each sector of the child's environment encompassed by the system of care. These changes make the child's interaction with it more manageable; and that is intrinsically therapeutic.

Some people object to this point of view, preferring instead to make mental health treatment more central. Our view is that while it is important, it is not central unless the therapist is reorganizing the interaction between the child and his or her environment. It is precisely because those interactions are so difficult to



Therapeutic Case Advocacy:
A Multi-level Model for Interagency Collaboration to Improve Services for Emotionally Handicapped Children and Their Families

change that this model is a multi-level model. In many situations, only concurrent interventions at all three levels can mobilize the resources necessary to effect such changes.

Comprehending the model is made difficult by its complexity. In part, this is because in practical terms it is three models in one. It is a *practice model* for working directly with emotionally handicapped children and their families. It is also an *organizational change model* for managing the conflict within organizations that is generated by the practice model. And it is an *interagency collaboration model* for implementing (creating and sustaining) the systems of care for individual children and their families. The diagram is an attempt to describe the model's three levels in one picture.

What this diagram still does not depict adequately is how actions taken at one level have important effects on the other two levels. For example, when a worker using this model unites his agency and several others with the child's parents, extended family, and church to design and implement a system of care, the worker is engaged simultaneously at all three levels. The initiative of his agency is an incentive for other agencies to collaborate, as is the participation of representatives from the child's personal community. Simultaneously, the resources made available through the interagency level provide both incentive and enhanced capacity for those at the case level to attempt modifications in the instructions, supports, and rewards they bring to the child's interaction with their environment.

Conclusion

This model is still in the process of development. We do not claim to be its sole inventors. Many others in the field have provided us with ideas, clarifying suggestions, and encouragement to proceed further in its development, demonstration, and evaluation. At the present time, therefore, our efforts are directed at the preparation of a training guide and an evaluation procedure. These will allow us to pilot test the model's introduction into a community and document its effects.

We continue to learn of others' efforts that are similar or at least compatible with ours. We are most eager to pursue the possibility of arranging a national conference at which those working in these ways on behalf of emotionally handicapped children and their families could meet and share their experiences. If you wish to participate in such a conference or to obtain additional information about Therapeutic Case Advocacy, please address your inquiries to us c/o Marilyn C. McManus, Resource Services Coordinator.

Thomas M. Young, Ph.D., Principal Investigator, Therapeutic Case Advocacy.

Case Management or Care Management?

Some of our colleagues have asked whether Therapeutic Case Advocacy is not just a form of intensive case management. Others have questioned our use of the phrase care management instead of the more familiar case management. We would like to take this opportunity to clarify our own point of view on the issues raised by these questions.

Both questions require a generally accepted definition of case management from which to proceed. That, of course, is part of the problem. As Weil, Karls, and Associates have said in *Case Management for Human Service Practice*, "case management is a developing method of service coordination and accountability in the human services." (Weil, et. al. 1985:1) Recognizing the diversity of conceptions inherent in a developing concept, they supply their own definition. "Case management is a set of logical steps and a process of interaction within a service network which assure that a client receives needed services in a supportive, effective, efficient, and cost effective manner." (Weil, et. al. 1985:2)

They note that "throughout its history, case management has had dual sets of goals -- one set related to service quality, effectiveness, and service coordination and the other related to goals of accountability and cost effective use of resources." (Weil et. al. 1985:2)

Care management is very much "a set of logical steps and a process of interaction within a service network" with goals of maintaining the provision of effective, coordinated services. But it is not concerned with efficiency or cost effectiveness. It is concerned only with the qualitative response of the system of care created

through use of the Therapeutic Case Advocacy approach. Nor is it concerned with accountability, except to the child and his or her parents. Finally, unlike case management, **care management** includes persons in the informal or personal community of the child and family.

We think these are very important differences. Too many applications of the case management concept have been "geared to the needs of the service network" rather than to the individual needs of clients and the development of resources to meet those needs. The planned inclusion of the child and family's personal community is part of Therapeutic Case Advocacy's view that the system of care will be managed best by the people who care the most. Together, we think these two differences shift the focus in a fundamental way from the management of a case to the continuation of personal care. As the late Nicholas Hobbs put it: "No one wants to be a 'case', and no one wants to be managed." (Hobbs, 1979:30)

Modrcin, Rapp, and Chamberlain, in their work to develop a model of case management for use with (adult) psychiatric disabled populations, outlined the many roles case managers were expected to fill and noted that they varied according to which model for case management was being used. They observed that the intensity of the case management process increases as the case manager assumes a greater number of roles. (Modrcin, et. al. 1985:35-40) In this sense, Therapeutic Case Advocacy certainly is intensive, requiring a worker to fill the roles of counselor, advocate, broker, manager, coordinator, spokesperson, and (at times) therapist. But, obviously, there is much more to Therapeutic Case Advocacy than managing cases. The organizational level of the model, particularly, adds a new dimension to most other models of case management.

Modrcin, et. al. also reviewed case management research. They found "substantial disagreement over the best way to operationalize case management"; "no conclusive evidence that case management significantly improves care" for the chronically mentally disabled (adult) population; and "experimental studies comparing models of case management .... non-existent." (1985:55-57)

More importantly, perhaps, for this discussion are the findings they culled from descriptive studies of case managers in mental health settings. These findings suggest that the case managers preferred not to be identified as such, spent most of their direct client time engaged in counseling or psychotherapy, and underutilized community resources on behalf of their clients. (1985:45-46)

We think the research suggests that, at least in mental health settings, the therapist-case manager dilemma first articulated by Lamb (1980) remains unresolved. And further, both the substantive content of case management and its efficacy remain undetermined. For these and other reasons, we have attempted to develop a model of helping, Therapeutic Case Advocacy, with a distinct role for care management within it.

Therapeutic Case Advocacy views the coordination of formal services and natural helping resources as central rather than auxiliary. Its foundation is the use of case advocacy at each of the three levels described in the lead article and its goal is to modify those interactions between the child and his or her environment that are handicapping. Instead of wrapping auxiliary services around mental health treatment, Therapeutic Case Advocacy sees the system of care that such services make possible as intrinsically therapeutic. In these ways, Therapeutic Case Advocacy is of a different order than any model of intensive case management.

Thomas M. Young, Ph.D., Principal Investigator, Therapeutic Case Advocacy

References

Hobbs, N. November 1979. *Helping Disturbed Children: Psychological and Ecological Strategies, II: Project Re-ED, Twenty Years Later.* Center for the Study of Families and Children, Vanderbilt Institute for Public Policy Studies, Vanderbilt University.

Lamb, R.H. 1980. "Therapist-Case Managers: More Than Brokers of Service." *Hospital and Community Psychiatry*, 31, 11, 762-764.

Modrcin, M., Rapp, C. A., and Chamberlain, R. 1985. *Case Management with Psychiatrically Disabled Individuals: Curriculum and Training Program.* Lawrence, Kansas: The University of Kansas, School of Social Welfare.

Weil, M., Karls, J. M., and Associates. 1985. *Case Management in Human Service Practice.* San Francisco: Jossey-Bass.

Interagency Collaborative Efforts

In the last issue of *Focal Point* we asked for information regarding programs using interagency collaboration to establish comprehensive systems of care for seriously emotionally handicapped children and their families. The following is a summary of the responses we received.

LANE COUNTY DIRECTION SERVICE
Eugene, Oregon
Marshall Peter, Executive Director

The agency addresses clients' needs by arranging coordinated interdisciplinary/inter-agency service planning on both a long range and short term basis, mediating between parents and professionals and providing materials for training workshops.

LANE COUNTY JUVENILE DEPARTMENT
Eugene, Oregon
Kevin Collins, Program Manager

Many juvenile offenders are considered behaviorally disordered or emotionally disturbed. Juvenile department staff make daily contact with clients' family, school, work, recreational and other settings to monitor client performance and environmental support. Their interagency teams have included judges, police officers, probation and parole officers, training school personnel, special educators, mental health providers, child welfare workers, recreation workers, and alcohol and drug treatment staff.

WEST VIRGINIA DEPARTMENT OF MENTAL HEALTH/ OFFICE OF BEHAVIORAL HEALTH SERVICES/ CHILD AND ADOLESCENT SERVICE SYSTEM PROGRAM
Charleston, West Virginia
Susan Mann, Program Coordinator

This new organization is planning a statewide conference designed to generate a sense of interagency ownership of the problems associated with serving children with serious emotional handicaps. They may develop a task force comprised of conference participants who will outline interagency protocol recommendations.

MAINE DEPARTMENT OF MENTAL HEALTH AND MENTAL RETARDATION/ BUREAU OF CHILDREN WITH SPECIAL NEEDS/ CHILD AND ADOLESCENT SERVICE SYSTEM PROJECT
Augusta, Maine
James B. Harrod, Ph.D., Technical Assistance Coordinator

The project has three sites (Bangor, Portland, and Saco) and is the central referral point for parents, mental health professionals, educators, and others who serve children with serious emotional handicaps. The group works closely with several service systems, including education, mental health, child welfare, and juvenile justice. Services are tailored to the strengths and needs of the child. Transition services are coordinated and parents are assisted with education, self-help, and other support activities.

CONTINUUM OF CARE FOR EMOTIONALLY DISTURBED CHILDREN
Columbia, South Carolina
Jeanne Rivard, Coordinator of Program and Staff Development

This small state agency's mission is to ensure continuing delivery of appropriate services to seriously emotionally disturbed children whose needs are not met by existing services and programs. Each child is assigned a service coordinator who provides case advocacy and management services.

THERAPEUTIC IN-HOME EMERGENCY SERVICES: A PROGRAM OF THE CRISIS INTERVENTION CENTER OF STARK COUNTY AND CASSP
Canton, Ohio
Carole Pastore, Program Coordinator

The center offers intensive in-home crisis intervention and family therapy to prevent out-of-home placements. Ongoing services are provided following the period of crisis intervention. Therapists are available 24 hours a day.

CHILD AND ADOLESCENT SERVICE CENTER DAY TREATMENT PROGRAM
Canton, Ohio
Sandra Dragomire, M.A., Associate Director

The program relies upon a multidisciplinary team and an active case management system. Case managers follow-up on recommendations, which may range from community/home visits to contracts with social service systems.

The Personal Community

We all belong to at least one community and many of us belong to several. From our community affiliations we develop relationships with individuals we trust and seek out to help us interpret our experiences in the world. Many families and particularly those with seriously emotionally handicapped children need the support of this kind of community structure to handle the pressures they face. Workers, too, need a source of support and encouragement in serving emotionally handicapped children and their families.

Systems of care can be structured in ways that support both clients and professionals by providing a collaborative environment conducive to addressing the needs and solving the problems encountered by seriously emotionally handicapped children and their families. Such care systems impart a sense of 'community' to their members; that is, a common notion of purpose, belonging, value to the group, and mutual support. In particular, such a system of care will validate the client's (child and family) role in the treatment process, while relieving professionals from the burden of providing service in isolation from other professionals and the family's natural support network. A system of care that supports clients, professionals, and other concerned individuals is what we call a "personal community."

In addition to including individuals important to serving the seriously emotionally handicapped child and family comprehensively, a system of care is a personal community when it encourages the development of supportive relationships among its members and is flexible, dynamic and, at times, even fun. The individuals involved come to recognize their interdependence and how they can function in complementary fashion. As a result, all of its members are empowered and supported in working on behalf of a particular child and family. The personal community is personal in the sense that it pursues *client-specific* needs and goals through social service systems that are essentially impersonal.

Each system of care, then, can be structured to serve as a personal community. It can contain the peers, mentors, friends, and other people we need to generate and maintain focus, values, and goals. For seriously emotionally handicapped children, their families, and their workers this type of system of care envelops them in a climate that supports and empowers them in what tends to be very demanding and often frustrating work.

James L. Mason, Project Manager, Therapeutic Case Advocacy

Process Evaluation of Interagency Collaboration Effort

The Therapeutic Case Advocacy Project (TCA) conducted a process evaluation of an interagency collaboration effort called CAPS, funded by Multnomah County, for the Portland metropolitan area. This undertaking encouraged community mental health centers to work with other child serving agencies in the community to provide comprehensive, integrated services for children and youth with emotional handicaps. TCA staff were involved in the planning and implementation of the CAPS project, as evaluators and consultants. At the end of the project's first year, TCA staff submitted a process evaluation to the County which helped persuade the Multnomah County Board of Commissioners to fund the effort for another year.

The CAPS project model is similar to that being developed by the Therapeutic Case Advocacy Project, especially in the area of team planning on the case level to develop a system of care for each child. Due to the interest expressed in this local effort to implement interagency collaboration at the practice level, TCA project staff edited the process evaluation for distribution to those in other communities concerned with line level implementation of collaborative efforts. The evaluation report documents the planning process -- its problems, compromises, successes, and pitfalls. The report also includes a description of the team process and recommendations based on both participants' and administrators' observations. To order a copy of this report, see page 11.

Families as Allies Regional Conferences

Strategies to improve and promote collaborative working relationships between professionals and parents of children with serious emotional handicaps were the focus of four Families as Allies conferences held throughout the country during May and June. Equal numbers of parents and professionals met in regional conferences held in Kansas, New York, Alabama and Indiana.

All four regional conferences addressed problems of current service delivery systems for children with emotional handicaps and their families, barriers to collaboration between parents and professionals, and strategies to enhance parent and professional partnerships. Participants in each of the regional conferences attended as members of state delegations composed of parents, policy makers, program administrators, and direct service providers.

Panels of parents and professionals in **Overland Park, Kansas**, described barriers to effective services, and the successes and frustrations in establishing a partnership between parents and professionals. The panel members discussed common problems such as misdiagnosis, the lack of respite care for parents, lack of communication between agencies in planning, problems of transportation, and lack of comprehensive insurance to cover the costs of care and treatment. Panel members emphasized the importance of parent and professional collaboration to enhance parents' roles as sources of information about their children, and fully involve parents as team members in the planning, provision and evaluation of services. Parents were urged to recognize the limitations and constraints experienced by providers, and to become involved in local parent support and advocacy groups to assist in the improvement of services for children with emotional handicaps.

The **Albany, New York** conference opened with a "Challenge to Partnership" by a professional and a parent. Obstacles to parent-professional collaboration were addressed through a psychodrama experience that demonstrated that both parents and professionals experience many of the same frustrations in trying to reach a common goal -- a better, more responsive system of care. The participants then engaged in small group, structured experiences which identified ways parents and professionals can collaborate in effecting change. A panel presentation discussed the organization of parent support and self-help groups in a variety of settings.

Participants in the **Mobile, Alabama** Families as Allies conference attended a variety of workshops dealing with support groups for parents, special education laws, working with cultural and ethnic minorities, and dealing with multiple systems of care. Plenary session panels spoke to the need for parent-professional collaboration and specific techniques and strategies for creating and nurturing such collaboration. A film festival on the second evening of the conference provided participants an opportunity to view selected films on a variety of issues concerning services to youth and their families, including program examples and topical issues such as AIDS education.

The Families as Allies Conference in **Bloomington, Indiana**, spoke to a wide array of problems and issues faced by those seeking to improve the system of care. Workshop topics included respite care, educational rights, legislative and case advocacy, case management systems, parent support groups, and community advocacy strategies. Keynote speakers discussed the nature of the current crisis in service provision to children with emotional handicaps, the importance of the parent-professional partnership, and some recommended future directions.

State delegations at each of the regional conferences met to identify barriers to collaboration and strategies to promote collaboration within their individual states. Members of each state delegation left the conferences with a plan of action for their state, many of which included proposals to improve coordination of advocacy groups, develop parent support groups, develop parent information packets, and offer state level Families as Allies conferences.

NOTES & COMMENTS

IN MEMORIUM

We were saddened to learn of the death of Art Sands, the administrator of the Kansas Child and Adolescent Mental Health Services Office. We extend our sympathies to his family and friends. In addition to the personal loss to those closest to him, his death is a loss nationally to the Child and Adolescent Service System Program, as well as to the people of Kansas. We will remember him for his boundless energy and devotion to children's mental health services.

RESEARCH AND TRAINING CENTERS' CONFERENCE AND CONGRESSIONAL RECEPTION

The National Association of Rehabilitation Research and Training Centers (NARRTC) held its ninth annual training conference in Washington, D.C. in May. The thirty-six rehabilitation research and training centers funded by the National Institute on Disability and Rehabilitation Research (NIDRR) are all NARRTC members. Highlights of the conference included speeches by David Gray, Ph.D., NIDRR director and the presentation of the association's Distinguished Service Award to Connecticut Senator Lowell Weicker, Jr.

The theme of the conference was facilitating personal independence through research. Participants shared their research with one another and explored methods of enhancing personal independence through minimizing physical impairments, improving the community environment, improving vocational opportunities, minimizing barriers found within particular cultures, and improving family opportunity and community linkages.

NIDRR Director David Gray explored the concept of interdependence. He emphasized the coequal relationship between professionals and disabled patients or clients. For example, the responses of doctors and patients are not independent; they are interdependent. Success requires mutual effort and respect.

NARRTC's Distinguished Service Award was presented to Senator Lowell Weicker, Jr. at the association's first Congressional reception. The reception, which was held in the Rayburn House Office Building, provided the association with an opportunity to honor a member of Congress who has contributed greatly to rehabilitation research. Invited guests included members of Congress, their assistants, guests from NIDRR and other government agencies involved with rehabilitation research. Each of the research and training centers had the opportunity to exhibit its products and display its significant accomplishments.

CASSP PROJECT DIRECTORS MEETING

The Child and Adolescent Service System Program (CASSP) project directors held their Spring meeting in Portland. Ira Lourie, Assistant Chief of the Community Service Systems Branch of the National Institute of Mental Health, announced that CASSP would achieve branch status. CASSP will have the distinction of becoming the first children's branch within NIMH.

Featured presentations included an overview of the Medicaid program, a summary of the use of media by mental health agencies, a review of paraprofessional partnerships with troubled youth in Idaho, and reviews of the Kansas Family Input Project and Washington state's Strategic Planning Training Project. The staff of the Portland Research and Training Center presented overviews of the Therapeutic Case Advocacy model and the Youth in Transition Project, as well as a review of videotaped and written resources designed to promote parent involvement.

The highlight of the meeting was a one day "Focus on Families" session. The seventy participants explored ways to facilitate collaborative efforts between families and professionals. Participants explored the similarities and differences in the agendas of CASSP personnel and families, strategies for involving families, the lack of available respite services, and CASSP directors' need for knowledge about how to assist in the development of parent support groups. The Georgetown University CASSP Technical Assistance Center is currently preparing a summary of proposed solution strategies.

The Fall CASSP Project Directors meeting will be held September 14-15, 1987 in Washington, D.C.

continued on last page

Research and Training Center Resource Materials

☐ *Annotated Bibliography. Parents of Emotionally Handicapped Children: Needs, Resources, and Relationships with Professionals* *
Covers relationships between professionals and parents, parent self-help, support and advocacy groups, parent participation, parents' problems and guidelines.

☐ *Annotated Bibliography. Youth in Transition: Resources for Program Development and Direct Service Intervention**
Transition needs of adolescents: educational and vocational issues, programs and curriculum, research overviews, interpersonal issues, skills training.

☐ *Child Advocacy Annotated Bibliography*
Includes selected articles, books, anthology entries and conference papers written since 1970, presented in a manner useful to readers who do not have access to the cited sources. $7.00 per copy.

☐ *Families as Allies Conference Proceedings: Parent-Professional Collaboration Toward Improving Services for Seriously Emotionally Handicapped Children and Their Families**
Held in April 1986 and attended by delegations from thirteen western states. Includes: agenda, presentation transcriptions, biographical sketches, recommendations, worksheets, and evaluations.

☐ *Gathering and Sharing: An Exploratory Study of Service Delivery to Emotionally Handicapped Indian Children*
Findings from Idaho, Oregon, and Washington, covering current services, successes, service delivery barriers, exemplary programs and innovations. $2.00 per copy.

☐ *The Multnomah County CAPS Project: An Effort to Coordinate Service Delivery for Children and Youth Considered Seriously Emotionally Disturbed*
A process evaluation of an interagency collaborative effort is reported. The planning process is documented and recommendations are offered. $3.00 per copy.

☐ *National Directory of Organizations Serving Parents of Seriously Emotionally Handicapped Children and Youth*
The U.S. organizations included provide one or more of the following services: education and information, parent training, case and systems level advocacy, support groups, direct assistance such as respite care, transportation and child care. $5.00 per copy.

☐ *Parent Information Workbook on Emotional Handicaps*
This self-teaching workbook for parents addresses topics such as parents' feelings about themselves and their children, labels and diagnoses, types of professionals and treatments, and legal issues. Single copies free to parents of children with emotional handicaps while supplies last. All others, $3.00 per copy.

☐ *Parents' Voices: A Few Speak for Many* (videotape)
Three parents of children with emotional handicaps discuss their experiences related to seeking help for their children (45 minutes). A trainers' guide is available to assist in presenting the videotape. Brochure describes the videotape and trainers' guide and provides purchase or rental information.

* One copy free per address while supplies last.

ORDER FORM AND MAILING LIST Research and Training Center

☐ Please send me the publications indicated above. $_____ enclosed as appropriate.

☐ Add me to your mailing list. ☐ Take me off your mailing list.

☐ Change my address as noted below.

☐ List my organization in the national directory. (The Research and Training Center will contact you.)

NAME _____

ORGANIZATION _____

STREET ADDRESS _____

CITY/STATE/ZIP _____

TELEPHONE _____

CHECKS PAYABLE TO: Regional Research Institute for Human Services
MAIL TO: Resource Services Coordinator, Research and Training Center, Regional Research Institute for Human Services, Portland State University, P.O. Box 751, Portland, Oregon 97207-0751, (503) 464-4040

NOTES & COMMENTS continued from page 10

WASHINGTON STATE FAMILY INITIATIVE

Washington State CASSP project staff are developing a comprehensive family support model that includes crisis resolution, education, skills development, support and advocacy. They are seeking curricula that have been developed or can be easily adapted for use with families with children who have emotional/behavioral difficulties. Topical areas include effective verbal/non-verbal communication, problem solving, stress management/coping skills, behavior management, social support network development, service systems and case advocacy. If you know of such materials, please contact: Dennis Olson, Washington State CASSP Project, MS: OB-42F, Dept. of Social and Health Services, Mental Health Division, Olympia, WA 98504.

NATIONAL SCHOOL STUDY

Jane Knitzer, author of *Unclaimed Children*, and her colleagues at Bank Street College are conducting a national study of how well schools respond to children with emotional and behavioral difficulties. She would welcome any information about individual programs and/or school districts that are particularly responsive to the needs of troubled children, and their families. If you know of such programs or school districts, or wish to share other perspectives on the issue, she would welcome hearing from you. Contact her at: Bank Street College of Education, 610 West 112th Street, New York City, New York 10025, (212) 663-7200.

TELEPHONE NUMBER CHANGE

The prefix for all Portland State University telephone numbers has changed. The Research and Training Center's new telephone number is (503) 464-4040.

FOCUS: YOUTH IN TRANSITION

The Youth in Transition Project is developing an approach for addressing transition issues faced by emotionally handicapped adolescents as they leave youth-serving systems and move toward the assumption of adult roles. The next issue of *Focal Point* will feature the Youth in Transition Project. We would like to identify innovative transition programs which serve emotionally handicapped adolescents. Programs should be oriented to facilitating the adjustment of emotionally handicapped youth to adult roles. Social skills training, vocational opportunities, and independent living experiences are all critical components of a transition approach. If you know of programs or models for youth with emotional handicaps that have a transition focus, please notify: Matthew J. Modrcin, Youth in Transition Project Director.

PORTLAND STATE UNIVERSITY
Research and Training Center
Regional Research Institute for Human Services
P.O. Box 751
Portland, Oregon 97207-0751

Nonprofit Org.
U.S. Postage
PAID
Portland, OR
Permit #770

Janet Drill
Department of Information Services
The Council for Exceptional Children
1920 Association Drive
Reston, VA 22091